

The impact of a support program for children with a chronic condition on psychosocial indicators

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Note: Tables appear at the end of the document.

Abstract

Children with chronic conditions are at risk for adverse psychosocial outcomes that may become barriers to optimal coping. Support programs for pre to early adolescents with a chronic condition are neglected in the literature. We conducted a pre-post intervention study to evaluate a pilot psychosocial support program for children with a chronic condition (aged 10-14 years) that aimed to enhance coping abilities. Twelve parent-child dyads participated in an 8-week support program. There was a significant increase in self esteem of children, a reduction in anxiety symptoms, and improved perceptions of family support at 3 month post group assessment. Identified coping strategies on the Children's Coping Strategies Checklist Revised found no statistically significant differences from pre to post assessment in measures of coping strategies, but mean scores indicate an increase in active, avoidant, and support seeking coping styles from pre to post intervention. Psychosocial support programs are an effective strategy to improve a range of outcomes for children but it is difficult to recruit sufficient participants into such programs.

Key words: children, chronic conditions; psychosocial support program; coping

Introduction

Around ten to fifteen percent of children under the age of 18 years have one or more chronic conditions that limit daily activities or cause disability (Newacheck 1994; Geist Grdisa & Otley 2003; Sein 2001). Children with a chronic condition face complex physical and emotional developmental challenges, particularly during adolescence. At this time the child experiences rapid physical growth, the development of secondary sexual characteristics and significant cognitive and psychosocial development that have a complex and bi-directional interaction with their chronic condition (Newacheck McManus & Fox 1991; Neinstein 2001). School years can be difficult due to teasing, trouble making friends, and high rates of absenteeism particularly for children with asthma, diabetes and juvenile chronic arthritis (Geist et al 2003; Trachtenberg & Batshaw 1997). Children with a chronic condition are also at risk of mental health problems such as anxiety, depression and social withdrawal (Silver Westbrook & Stein 1998; Cohen 1999; Geist et al 2003). Despite these difficulties, a number of protective factors do exist,

including a positive temperament, above-average intelligence, social competence, a supportive relationship with at least one parent, family closeness, and adequate rule setting by parents (Neinstein 2001).

Psychosocial adaptation to a chronic condition is an evolving, long-term, complex and somewhat unpredictable course (Livneh 2001). Adaptive resources, such as effective coping strategies can help children with a chronic condition manage stressful experiences (Kazak 1992). The promotion of positive coping styles is particularly important in enhancing resiliency in older children (Charron-Prochownik 2002). Active coping (such as making decisions, seeking social support) is associated with better condition-related adjustment whereas avoidance coping is predictive of adjustment difficulties (Frank Blount & Brown 1997). Investigations of the coping styles of children with diabetes found avoidant behaviour was related to poorer social adjustment and poor adherence to treatment (Grey Cameron & Thurber 1991). Adolescents who demonstrated social support seeking coping behaviour, discussed their daily problems with others and were found to possess better social skills and display more assertive behaviours than adolescents less likely to seek social support (Meijer Sinnema O-Bijstra et al 2002).

There is a need to identify and assist children at risk of poor coping. Many stressful issues for children and their families can be anticipated and managed through education and supportive family-centered services that aim to reduce condition demands, increase family resources, create affirmative meanings and support the total family system (Cohen 1999). Yet children and families most at risk are less likely to approach health services (Early & Glenmayer, 2000). To address these needs we developed a psychosocial support program for pre to early adolescent children and their families to promote coping. This paper describes the development of the parallel child/parent programs but reports only on the outcomes for the children.

Psychosocial support program intervention

There have been several programs developed in Australia to provide support to children with a chronic condition, and yet these programs are often not rigorously evaluated or replicated. The Chronic Illness Peer Support Program (ChIPS), for example, began in 1992 in Melbourne to address the psychosocial needs of patients who commonly feel isolated. After completion of an eight week program participants can complete a three day leadership training course. Graduates of the course are then eligible to co-facilitate a ChIPS program with a health professional. The group promotes learning and sharing with people who understand what it is like to live with a chronic condition. Despite its popularity and ongoing government funding, the program has not been independently evaluated.

Like ChIPS, our pilot program was designed around peer support and addressed common difficulties associated with chronic conditions despite different specific symptoms. Research findings suggest there are few, to no differences in the psychosocial impact of a chronic condition across diagnoses (Eiser 2003; Madden 2003). It is possible for children with different conditions to benefit from inclusion in the same group. Although the ChIPS program was specifically designed for children with a chronic condition (Olsson

& Boyce 1995), our program extended these principles through a parallel intervention with parents and was called the Child And Parent Support program (CAPS). We proposed that the inclusion of parents in their own peer support group would be of added benefit to the parent, the child, and family system as a whole. Using existing family strengths and capabilities, the peer support strategy aimed to promote families' abilities to mobilise resources, strengthen social networks and develop new coping resources. The support program was based on a number of principles derived by Dunst and Trivette (1988). First, the intervention is based on identified needs. The first session for children focuses on getting to know each other and gaining insight into the chronic conditions of others. The parallel session for parent prompted reflection on the positives and challenges associated with having a child with a chronic condition. Themes to be addressed in subsequent sessions related predominantly to managing conflict, self esteem building, school issues and relationships with family and friends. Second, the program focuses on strengths, or the things that the child already does well as a basis for mobilising resources. Third, the program builds and strengthens natural support systems or informal sources of support (rather than encourage dependence on the health care system). Fourth, the program creates opportunities for children to display their strengths and become self-sustaining in their coping strategies. In this way the group provides opportunities for the children to help themselves and each other. The CAPS program offers a group support strategy to improve the psychosocial wellbeing of children and their parents. The outcomes of the group are to:

1. Facilitate better self-care in children with a chronic condition.
2. Increase well-being and quality of life for the child and family
3. Decrease psychological symptoms of distress for both child and parent and prevent psychological distress in the future.

METHOD

Recruitment

Advertising of the program was conducted within the Health Services District via brochures, information sessions and posters provided to staff within the hospital, General Practitioners, Pediatricians, School Guidance Officers and specialist groups providing support for children with chronic medical conditions. Information about the program was provided to the general public via newspaper and radio community service announcements. Referrals to the program came through health professionals or alternatively families were able to contact the project officer directly.

Eligibility criteria for participation in the program were as follows: (a) child aged between 10-14 years, (b) presence of a chronic medical condition in the child, and (c) willingness of the child and one parent to participate in the program. Exclusion criteria included: significant intellectual impairment, the presence of a chronic and severe psychiatric condition, and being in the terminal stage of a condition.

Measures

Demographics and condition history: A brief parent self-report measure was administered to determine family composition and demographic information. Parents' perceptions of condition severity, difficulty in coping with the child's medical condition,

and perception of how well they coped with the child's medical condition were rated using a 10 point likert scale, with increasing scores indicating greater levels of difficulty.

The Child Behaviour Checklist (ages 6-18) (CBCL; Achenbach 2002): The CBCL is a standardized measure of parental perception of their child's behavioural problems and competence. The CBCL has 113 items related to a variety of child problems. Items are scored from 0-2. The scores can be summed to produce 8 syndrome scale scores (anxious/depressed, withdrawn/depressed, somatic complaints, social problems, thought problems, attention problems, rule breaking behaviour, and aggressive behaviour). From the 8 syndrome scales the CBCL provides 2 broad scales, internalizing and externalizing. The CBCL also assesses social competence, producing a total competence score and three sub scales (activities, social, and school). The validity and reliability data for the CBCL is reported to be excellent and the measure is widely used in research and clinical practice.

The Family Environment Scale -Real (FES; Moos & Moos 1986): The FES is a 90 item forced choice measure of the current social climate within a family as perceived by the respondent. The FES has ten 9-item sub-scales and two summary indices, the Family Social Integration Index and Family Relationships Index, which are comprised from combinations of the sub scales. The Family Relationships Index is reported to have good internal consistency and is widely reported as a measure of family support (Moos & Moos 1994). The sub scales of the FES include: Cohesion, Expressiveness, Conflict, Independence, Achievement Orientation, Intellectual-Cultural Orientation, Active Recreational Orientation, and Moral Religious Orientation Organisation, and Control. The internal consistency of the scales on the FES is reported to range between .61 (independence) to .86 (cohesion, moral religious orientation, and cultural orientation).

Measures completed by Children

The Coopersmith Self Esteem Inventory (CSI; Short school form; Coopersmith 1981): This is a 25 item, forced choice, self report measure designed to assess self perceptions in peer, parent, school, and personal interests. Respondents indicate whether the statement is "like me" or unlike me" when completing the CSI. The CSI is a widely accepted measure of self-esteem, which is reliable and valid enough for use in research.

The Revised Child Manifest Anxiety Scale (RCMAS; Reynolds & Richmond 1978) is a 37 item forced choice self report inventory to the presence of cognitive, behavioural or affective symptoms of anxiety or negative affect. The RCMAS is widely used and is reported to have good reliability with the internal consistency of the total anxiety scale reported as .83.

The Child Depression Inventory (CDI; Kovacs 1992): The CDI is a 27 item measure designed to assess depressive symptoms in children. Each item has three self report statements, graded in severity, which are scored between 0 to 2. Respondents complete the CDI based on how they have been feeling over the past few weeks. The internal consistency of the CDI ranges from .71 to .89.

The Children's Coping Strategies Checklist Revised (CCSC-R1; Ayers et al 1996): The CCSC is a self report inventory on which children rate on a four point likert scale, the degree to which they use a particular coping strategy. Higher scores are indicative of greater endorsement of the coping strategy. Forty-five items from the CCRC-R1 incorporating the three major factors were included. The scales included Active Coping Strategies (Problem Focussed Coping and Positive Cognitive Restructuring), Avoidance Strategies (Avoidant Actions, Repression, Wishful Thinking) and Support Seeking Strategies (Support for Actions, Support for Feeling). The internal consistency of the factor and sub scales are recognized to fall within the range of .46 - .72.

Procedure

Eligibility criteria and information regarding the program were discussed during the first phone contact with the parents. At this time an assessment appointment was arranged. During the initial assessment interview informed consent was obtained from the parent and child, and individual and self-report questionnaires were completed. All assessment measures, with the exception the Child Behaviour Checklist (CBCL: Achenbach 2002) were re-administered at three months following group participation in the program.

SPSS Statistical Package (version 11.5) for Windows was used to analyse the data. The purpose of the analysis was to describe the group participants and investigate areas of change in children following participation in the program. Descriptive statistics were generated for demographic variables (including age, gender, socioeconomic status, and parental marital status) and for the dependant variables. Paired t tests were used to evaluate the impact of the treatment on the participants from pre to post testing.

Data screening

Prior to analysis, all scores were examined to check for the accuracy of data entry. The skew of the data was investigated, with a significant positive skew and kurtosis noted in the Child Depression Inventory (CDI) scores at pre assessment. The positive skew of the CDI scores can be expected as the measure is designed to assess psychopathology in clinical populations. As the sample in this study was drawn from children with chronic medical conditions rather than from a psychiatric population, it is not surprising that some of the scores are clustered at the lower end of the distribution. These results are similar to that attained within the normal population. A significant effect of kurtosis was also identified in the CDI scores at pre-assessment. Examination of the scores identifies extreme scores at either end of the distribution which impact on the effect of finding significant results, particularly influential in small sample sizes.

Results

Participants

Twelve children-parent dyads were recruited into the eight week pilot program. The chronic conditions of the children varied widely (See Table 1). The age of the children ranged from 10-14 years, with the mean age of 11.2 years. Mothers attended the parallel parent program in the majority (83%) of cases.

Insert table 1 about here

Screening assessment on the Child Behaviour Checklist (CBCL) by the parent to assess their child's current levels of functioning reveals varying degrees of problem areas and competencies within the group participants (See Table 2). All females fall within the normal range on scales assessing internalising symptoms whereas the majority of males fall within the clinical range on internalising symptoms. Externalising symptoms were found to be within the normal range for the majority of group participants, with only one male and one female falling within the clinical range. Total scale scores on the CBCL identify two participant scores within the clinical range, one male within the borderline range, and the remaining participants to be within the normal range. The Competence Scale scores identify three females to be functioning within the clinical range.

Insert Table 2 about here

Treatment effectiveness for children

To test the hypothesis that group participation would show a reduction in depressive symptoms and anxiety symptoms and an improvement in self esteem, active coping, support seeking coping, and an improvement in family support, descriptive statistics and paired t-tests were conducted investigating mean scores at pre and post assessment for measures completed by children.

The results of the assessment with children (see Table 3) on the Coopersmith Self Esteem Inventory indicate a significant increase ($t= 3.39, p<.01$) in self esteem attained from pre to post group assessment. The Family Relationships Index mean score increased, suggesting children had improved perceptions of their family support at post group assessment. The mean scores on the RCMAS show a reduction in anxiety symptoms reported from pre to post group assessment. At post assessment, the mean score for the group reduced to fall within the range consistent with scores attained in the standardisation sample of the RCMAS, for males and females (10.16-11.89) aged between 10-12 years (Reynolds & Richmond 2000). The CDI mean scores for depression show a 1.89 increase from pre to post assessment, with 89% of scores remaining below the 55th percentile on the CDI at post assessment (that is, non-clinical range). One score remained at the 58th percentile at post assessment; however this score was reduced from the pre assessment result which was within the 65th percentile.

Insert Table 3 about here

A t-test found no statistically significant differences from pre to post assessment in measures of coping strategies. Mean scores indicate an increase in active, avoidant, and support seeking coping styles from pre to post intervention.

At post group assessment mean scores of assessing the parental perceptions of the impact of the condition on the child reduced significantly ($t = 2.37, p < .05$). Further, the impact of the condition on the parent reduced with mean score reductions suggesting that the impact of the condition was perceived to be less on the parent and significantly less on the child, at post assessment.

Discussion

There are few published Australian studies that have systematically evaluated the impact of a psychosocial support program on a range of outcome variables for children. This study is unique in its focus on pre-adolescent children with a range of chronic conditions, emphasis on coping strategies, and use of a multidisciplinary team approach. Despite these strengths, there were a number of inherent limitations. Pilot studies are used to inform the adequacy of the sampling frame, suitability of the data collected, efficacy of the recruitment of participants and suitability of the timeframe and costs (Roberts 1998). In terms of sampling frame, participant numbers in the present study are very small and the results should be interpreted with caution. Because of the nature of the target group it was not possible to recruit a large representative sample, but we were able to recruit children with a range of chronic conditions. Recruitment was a major challenge, despite various advertising strategies including radio interviews, articles in newspapers and health district publications, health professional education activities on the project, letters to general practitioners, private consultants, nurse consultants, support group convenors (e.g., Asthma Foundation) and school counsellors in the District, and word of mouth. The original plan was to recruit a minimum of forty participants, half of which were to be randomly allocated to a wait-list control group. Slow recruitment of a small number of participants prompted the adoption of a simple pre-post evaluation design.

Despite the potential importance of support groups as a key intervention for parents and children with chronic conditions, there has been concern about the actual use of services, irregular attendance and attrition. Ireys, DeVer and Chernoff (2001) identified that support groups rarely enrol all eligible families. Despite the potential adverse outcomes for families with a child who has a chronic condition and their need for support, there is relatively little literature on factors that may hinder or facilitate attendance at psychosocial support groups.

Data collection in the present study involved a battery of standardized instruments that all revealed high Cronbach alpha reliability coefficients in both phases of the study (see Table 3). The administration of the tools was time consuming, required specialist training, and may have been a barrier to participation when individuals were informed of this requirement. Although, the attrition rate of participants in the study was relatively low, the detailed approach to the assessment of outcomes may limit replication by other clinicians who would not have sufficient financial resources to purchase the tools and time to comprehensively assess group participants at several time points.

The results of the present study may also be limited due to a possibility of response bias. Parents most interested in psychosocial support may have been more likely to participate and may have differed from non-respondents or individuals at greater actual risk of poor

copied. Some parents who do not attend groups may believe they are functioning quite well, that support groups are not necessary, or they have no specific problems at that time (Ireys et al 2001). Alexander (2000) concluded that clients and their families faced with a chronic condition must be willing to make a change in their life and willing to learn. The high rate of program completion in the present study may reflect in large part, satisfaction of parents and children with the group. Health professionals therefore need to play an active role in promoting the benefits of group participation and encourage at-risk families to follow through with the referral.

The results of this study confirm the value of psychosocial support groups in promoting the self esteem of children, reducing anxiety symptoms, and improving perceptions of family support. Identified coping strategies on the Children's Coping Strategies Checklist Revised found no statistically significant differences from pre to post assessment in measures of coping strategies, but mean scores indicate an increase in a range of coping styles (active, avoidant, and support seeking) from pre to post intervention.

Although active coping (such as making decisions) is associated with better condition-related adjustment, the present study also identified an increase in avoidance coping. Frank, Blount and Brown (1997) suggested that avoidance coping was predictive of adjustment difficulties, but this may not be the case when children appropriately use a balance of coping strategies according to their circumstances. Adolescents who demonstrate active and social support seeking coping behaviour may also use avoidance coping in social interactions so as not to alienate themselves from their peers. They may chose not to participate in a physical activity but form friendships in more sedentary groups. It may also be that avoidance coping strategies are more difficult to change and although participants in the present program adopted more active and social-seeking strategies they did not relinquish avoidance strategies.

In conclusion, psychosocial support groups enable children to identify, understand and manage the demands in life of having a chronic condition by applying balanced coping strategies. Children who participated in the support group were more likely to report an increased sense of self esteem and belonging, as well as skills to manage day-to-day situations. There are on-going difficulties with the recruitment of families to such programs and creative strategies using a range of program delivery methods such as intensive mode, home-based groups and on-line chat sessions may need to be investigated.

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Table 1: Participant profile

Gender	Age	Condition
Group 1		
F	11	diabetes
F	11	Friedriechs ataxia
F	10	Friedreichs ataxia
F	10	Cystic fibrosis
F	12	Arthrogryposis/visual impairment
F	13	diabetes
Group 2		
F	11	Cystic fibrosis
M	13	Cystic fibrosis
M	11	Caeliacs disease
M	10	lymphodema
M	13	asthma
M	11	Cystic fibrosis

Table 2: Parental Perceptions of Child's Condition

Measure	Mean	Standard Deviation	Range
Severity of Condition	7.0	2.35	5-10
Parental ability to cope with child's condition	5.33	1.73	3-8
Parental efficacy in coping with child's condition	3.33	1.50	1-5
Child Behavior Checklist Internalising	10.67	12.48	1-39
Externalising	10.44	1.32	2-35
Total	36.44	31.83	8-100
Competence	21.44	5.3	16-28

Table 3: Descriptive Statistics for Children at Pre and Post Assessment

Variable	Mean		Standard Deviation		Range		Alpha	
	pre	post	pre	post	pre	post	pre	post
FES – FRI	17.62	19.61	4.14	3.90	11-22	12-23	.71	.72
CDI	5.11	7.0	6.75	7.03	0-18	1-24	.88	.91
RCMAS	15.33	11.77	8.73	8.10	1-28	3-23	.92	.91
CI	16.33*	20.22*	6.30	4.20	6-23	12-25	.83	.83
CCSC-R1								
Active coping	58.11	59.78	15.11	10.09	24-77	45-73	.95	.87
Avoidance	31.22	33.78	7.26	5.87	20-40	26-44	.78	.74
Support seeking	23.0	25.78	9.21	4.79	9-35	18-33	.98	.76

Note: FES-FRI = Family Relationships Index from the Family Environment Scale; CDI = Children's Depression Inventory; RCMAS = Revised Child Manifest Anxiety Scale; CI = Coopersmeith Self Esteem Inventory- Short Form; CCSC-R1 = Children's Coping Strategies Checklist (PFC = Problem Focused Coping; SSS = Support Seeking Strategies) * = t-test indicates a significant difference between means from pre to post test assessment $p < .05$